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ABSTRACT

This newsletter article is concerned with understanding what schools can and must do to sustain life in the age of human immunodeficiency virus and Acquired Immune Deficiency Syndrome (HIV/AIDS). The article looks at the incidence of AIDS and reviews legislation related to AIDS infection and school attendance. School policy as it relates to students who have tested positive for HIV is considered. It is noted that the only known cure is prevention and the only prevention is active, effective education. Consequently, the state of HIV/AIDS education in the schools today is critically examined. The need for behavior modification in addition to knowledge about HIV/AIDS is discussed. The overrepresentation of young, black, and Hispanic persons among AIDS victims is considered, and the need for women to recognize the dangers of AIDS is emphasized. While prevention is stressed as the most desirable goal, when prevention efforts have not succeeded or when such efforts were nonexistent, the need for empowered care among AIDS victims is advocated. The need for health care for HIV/AIDS as a long-term chronic illness is stressed. The article concludes with a section on policy ideals. A sidebar called "AIDS 101" provides basic facts about HIV/AIDS. (NB)

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Making the most of the space between a rock and a hard place:

Living with HIV/AIDS *in* School

AIDS is everyone's problem, and everyone can be part of the solution.
—Mervyn F. Silverman, MD, MPH, President, American Foundation for AIDS research

There's no time for moral evasions and euphemisms or other genteel discretion in teaching young people who are either sexually active or on the brink of becoming so.
—from *Days of Grace: A Memoir* by Arthur Ashe, (tennis superstar, historian, and cultural commentator who contracted HIV through a blood transfusion and lived with the disease for five years)

The reality is that young people are infected with HIV and they're enrolled in the schools. These people lead normal lives—especially in the beginning stages of the infection. We need to educate ourselves to that fact and what it means.
—John Peter Wilhite, Education Director, AIDS Services of Austin

Look around. The red ribbons pinned to the chests of celebrities, activists, politicians, and just plain people this past spring signalled a reality check. First adopted to show solidarity with those who live with HIV/AIDS every day, the ribbons reflect the color of life, health, and blood. The reason for that choice is understandable: many have come to understand that living openly in the world with the human immunodeficiency virus (HIV)—which attacks the human immune system and causes Acquired Immunodeficiency Syndrome (AIDS)—is preferable to dying in silence from the disease. What we at *SEDLETTER* hope to do with this slate of wood pulp and ink is to help readers see how those who live with AIDS learn to replace angry cries of "Why me?" with the much more useful and courageous "Try me—if you must." In the process, we wagered that all of us would learn to see HIV awareness as more of an act than a euphemism.

To that end, we ambitiously set out in search of an "if-then" plan of action for this world-wide epidemic (a.k.a. "pandemic") whose spread defies reason as nimbly as it undermines the very education that can prevent the suffering in its wake. As usual, we ferreted out research, expert opinion, and commentary. We examined the virus from AIDS 101, to the history of the pandemic in schools, to the laws designed to protect us from our own fear of each other, to the people with HIV/AIDS who do daily battle with the denial and isolation that accompany the disease. But we also realized early in our process of understanding that mincing words about the sexuality, drug abuse, poverty, racism, and sexism that have made HIV/AIDS a sentence to hell on earth, served little purpose save to muddy already murky water. We steeled ourselves to face the hard facts that children and teens are having unprotected sex and/or shooting steroids and other drugs into their bloodstreams with shared needles in numbers sufficient to put the next generation of human kind at risk—not of school failure, or dropping out of school, or getting into trouble, but—of dying. We determined to look without shying away, wincing, or capitulating as have so many HIV/AIDS education efforts. Far from being offensive, we reasoned, straight talk on a virus that literally scares people to death should serve to allay fears and make everyone more human in the process of understanding. So, with unblinking, clear eyes, here's what we discovered and hope you'll share.

An undercurrent of numbing numbers

HIV is into the teenage population and it's spreading quickly and silently. . . . Adolescents are at the leading edge of the next wave of the epidemic.
—August 1993 statement by Karen Hein, Specialist in Adolescent Medicine, Albert Einstein College of Medicine

At the present rate of infection, by the year 2000—that's only seven years hence—40 million people will be infected with HIV, including 10 million young people. Adding to the 40 million who are infected, 10 million children are likely to be orphaned by the AIDS that has killed their parents.
—from Michael Ford's *100 Questions and Answers about AIDS*

The trend toward increasing numbers of women and babies with AIDS is expected to continue in the next several years. This should be *a national concern.*
—John Ward, Centers for Disease Control

No place in our society is HIV's preeminence more catalytic than in the nation's schools. According to the 1992 Congressional Select Committee on Children, Youth, and Families report, *A Decade of Denial: Teens and AIDS in America*, 75 percent of teen girls and 86 percent of teen boys become sexually active before they reach their 19th birthdays. That means most teenaged students may well be sexually active in any school at any given time. No matter how much or how little information on safer sex a school district permits in the classroom, at least half of young women and two thirds of young men are sexually active by age 15. The average number of different sex partners each has ranges from two to six individuals. Not only has the age of sexual initiation lowered in the past decade, but the number of adolescent premarital sexual partners has increased just as dramatically. It should come as no surprise that more than a million teenage women become pregnant each year, and one in six teens (or some three million a year) contracts a sexually transmitted disease (STD) each year. Although HIV/AIDS education and prevention efforts seem to have contributed to increased condom usage among sexually active teens, a full third of all teen females use no form of contraceptive at first intercourse, and most adolescent females delay contraceptive use for up to a year thereafter. Factor in the devastating truth of Center for Disease Control (CDC) estimates that a quarter of people who discover they are infected with HIV between the ages of 20 and 25 were infected as teens, and you begin to see that, no matter how you count them, the numbers are discouraging—even senseless—when the subject is HIV/AIDS.

Ironically, the most frightening number of all is the one that isn't being counted: A mere handful of states track HIV infection, and the CDC only collects such information in some 40 U.S. cities. Thus, an educated guess is all that exists to gauge the number of children and teens who are infected with HIV. The virus taps a few with symptoms, but educators, health care providers, and policymakers alike know that many, many more have no symptoms but carry the virus with them to school every day, blithely mature with it every day, and will someday die from the havoc the virus wreaks on their immune systems—every day.

And ignorance begot fear, that begot denial, that begot silence, that begot the spread of HIV, that begot death in the human family

We have killed each other—with our ignorance, our prejudice, and our silence. We may take refuge in our stereotypes, but we cannot hide there long. . . . If you believe you are safe, you are in danger. **—Mary Fisher, artist, mother of two, and person with HIV disease who spoke to the 1992 Republican National Convention**

After we played Chisum, my girls went through the line to shake hands, and their players were saying, "HIV, HIV." When we walked in the door, the Chisum students started saying things about diseases and HIV, and "don't touch me."

—Feb. 14, 1992 statement by girls basketball coach and Rivercrest High School Health Teacher (The school of 197 students underwent a media blitz last year after a counselor's unsubstantiated report that six local students tested HIV positive.)

Orlando, FL—*Ricky Ray, the eldest of three hemophiliac brothers once barred from school because they carried the AIDS virus, died Sunday. . . He was 15.*

—Associated Press, Dec. 14, 1992

Denying the impact of HIV/AIDS doesn't make it *not* so; it makes it *more* so. The Select Committee on Children and Families reports that teen cases of full-blown AIDS increased by 70 percent from 1990 to 1992: "HIV, the virus that causes AIDS, is spreading unchecked among the nation's adolescents, regardless of where they live or their economic status," the report begins. An international meeting on AIDS in Berlin last month likewise warned of the increase in HIV infections among teenagers.

The worst news, however, cuts deeper. Federal health officials and those on the local level continue to see evidence that young adults are not changing their sex- and drug- related behaviors sufficiently to significantly slow—let alone stop—the spread of HIV. That's an extremely frightening reality in light of new research that shows teenaged girls who have just reached puberty are more susceptible to the HIV infection than are older women. Apparently, in such very young women, the walls of the uterus are thinner—a characteristic that increases the opportunity for HIV infection. Postponing first intercourse could, according to the study, equalize the risk for HIV infections in these extremely young women. But such obvious conclusions offer small consolation in a world with a million teen pregnancies a year, a median age of 15 among girls for first sexual intercourse, and an HIV infection rate among girls of 4.2 per 1000 (nearly twice that of boys). A startling downside of this subpopulation's disproportionate infection, as a group of Chicago researchers note in the December 1992 *Journal of the American*

AIDS 101

HIV disease which leads to AIDS is a blood-born disease. Anybody can get it if the virus gets into their blood stream. That means HIV disease is spread through "unsafe" or "unprotected" sexual intercourse, blood transfusions, infected blood or the sharing of needles that have already been used for injections. Nobody can contract HIV disease from hugging, kissing, sharing food, or simply being near a person who is infected with the virus. Nobody contracted the disease from monkeys or mosquitoes, nor did the virus originate in these or any other known animal. And no student, according to the U.S. Department of Education's Office of Civil Rights, has ever been infected in the normal course of attending classes at school.

HIV is an equal opportunity virus, and AIDS is its indiscreet hitman. Together they feed a health epidemic of global proportions that is therefore more accurately known as a "pandemic." Because HIV/AIDS is present in every country on the planet, it's clear that the high-risk "groups" of the 1980's never existed. High-risk "behaviors" caused and still cause the spread of HIV. Indeed, modifying behaviors is the only way to control the spread of the disease. Experts who have worked for more than a decade to control HIV/AIDS warn that fear, ostracism, quarantine, prejudice, discrimination, and information that is merely heard rather than internalized have done more indirectly to spread the virus than any other factor or set of factors. Because all these human characteristics and flaws serve to sustain the status quo, the behavior changes that would allow societies to meet the HIV pandemic head-on are stymied and delayed if not prevented entirely. Anyone—whether they are gay, straight, or bisexual; black, white, yellow, brown, or some mixture of races and ethnicities; Haitian, European, Asian, or any other nationality; Christian, Muslim, Mormon or a practitioner of any other religion can contact HIV and get full-blown AIDS if the virus finds its way into that individual's blood stream. A child who is born to a mother infected with the HIV virus or who is "seropositive" has a 50 percent chance of contracting the disease. There is no treatment to prevent the the virus from infecting the child. Breast feeding is therefore discouraged if the mother is infected with HIV.

Although HIV disease is a comparatively difficult virus to contract, once in the blood stream it may not be detectable for six months. At six months, the virus can be detected through at least two reliable HIV antibody tests. Because HIV infection may exist in any body for as long as a decade or more without symptoms, the only way to be sure you are HIV positive or have the virus that causes AIDS is to have your blood tested. Given the stigma and violence that a fearful world has attached to the virus, anonymous testing is encouraged. Anonymous testing simply means that you are a given a number rather than giving your name to a tester. That number is attached to your blood sample, and that number is tested for HIV and contacted accordingly.

Once the virus enters the blood stream, it begins to break down the immune system of its host. The immune system agents known as the T-cells that allow the body to fight off infection are attacked and replaced by the virus that multiplies. A normal, healthy person has about 1,000 CD4 T-lymphocyte cells per cubic millimeter of blood. Once the T-cell count drops below 200, full-blown AIDS is usually diagnosed, and the body is most vulnerable to some 25 opportunistic diseases and cancers that eventually take the life of the host. About 30 percent of people who are HIV positive, contract an opportunistic disease within the first five years after testing HIV positive. The average lifespan after diagnosis of AIDS, according to the Centers for Disease Control, is from two to six years.

Only one in three or four of the babies who test HIV positive at birth are truly infected with the disease. Determining the child's HIV status can take up to 18 months after birth. About 50 percent of all persons who are HIV-positive regardless of their age develop opportunistic diseases within the first nine years of the infection. Thus, the fight against AIDS that may last for more than a decade is kin to the fight against many other long-term chronic illnesses. Life doesn't stop upon discovering one's infection; it continues. Services and the needs they are designed to meet don't cease, they are ongoing and vital. The immediate and only question to be realistically asked and answered is how do we live with HIV/AIDS. Only perhaps later—often much later—must the question of how do we die from AIDS be actively addressed. And, since all humans are mortals, that question and answer have always been a part of life. As 15-year-old, HIV-positive Anthony Godby Johnson notes in his biography, *A Rock and a Hard Place*: "At around three in the morning, the grate comes down . . . and it signals to me that the night is just about over. I feel as though I have tempted fate and made it through another day. No matter how horribly things are going or how sick I feel, the rickety sound of that grate tells me I am still alive. Again."

Medical Association, is the impending "social catastrophe" of the children who will be left orphaned by their largely female single parents who die of HIV/AIDS related illnesses. While the Panos Institute in Norway initiates its international study of "AIDS as a disease of the family," experts in the U.S.warn that AIDS is already creating a class of especially troubled and traumatized youth: Half the children who have had parents die of HIV/AIDS are teenagers whose sense of loss is compounded by their sense of embarrassment, secrecy, and anger.

But targeting subpopulations for special services is not sufficient to stem the tide of infection among teens nor the familial tolls it extracts. Surveys show that teens who have multiple sex partners are less likely to use condoms or otherwise protect themselves than are teens who are monogamous. The same devil-may-care behaviors also prevail, studies indicate, among people with partners who are intravenous drug users or practice unprotected sex. And, contrary to the popular myth that the majority of HIV infection occurs in large cities, a third of the AIDS cases among teens have been reported in areas with populations of less than 500,000.

As was the case in 1992 with the publication of *A Decade of Denial*, there is still no formal national health policy regarding adolescents and HIV. A full third of public school districts nationwide did not offer HIV education of any kind in 1990. And although Mary Futrall warned us then that "one in three teachers will teach a child with AIDS in the next five years," teachers and administrators continue to deny the pandemic's shadow on their classrooms. Meanwhile, despite a large body of research and practice that suggests linking schools to health and social services is a life-saving strategy, a paltry 300 schools in the entire U.S. maintain school-linked health facilities.

Granted, one or two isolated groups "optimistically" note that since AIDS has not yet been certifiably contracted by the meganumbers originally predicted, the threat may prove "hyped" or "false." Studies like that of the National Research Council, which contends HIV/AIDS has remained marginal because the majority of those it infects are members of marginal communities, at best validate the vulnerability of minority groups to the virus. At worst, say HIV/AIDS educators, such reports lull so-called "mainstream" Americans into a dangerously false sense of security. The Family AIDS Network and the National Commission on AIDS recognize the pandemic as a slow-moving iceberg whose tip is all anyone can point to. Further, they warn, such HIV marginalization provides readers with "another excuse not to care."

Reports, surveys, and analyses notwithstanding, the reality we hope to emphasize here is that just as people have survived the most heinous of blights throughout human history, there are those who are surviving the HIV blight by keeping full-blown AIDS at bay through education, nutrition, and lifestyle modifications. Clearly, denying information on sex and drugs to the nation's young people has done little to protect them from the natural maturation and risky behaviors that have been synonymous with adolescence for centuries. The social and racial stigma attached to the HIV/AIDS pandemic has torn it from the realm of health threat and smeared it into the purview of witch hunts and excommunication. As educator/evaluator W. James Popham asks, of what use are all the "success" indicators, the assessments, the interventions to build academic prowess, when the life and health of every student in school is endangered by ignorance of HIV disease and its transmission? "We're not talking about the merits of sending forth graduates who may know a little less social studies or mathematics than they should," chides Popham. "What good does it do to have students learn a few more vocabulary terms if they're not alive a decade later to use them?"

In the spirit of learning from the living how not to waste lives, it's word of the younger Ray brothers in Orlando that we pull from the wire. The same Associated Press story that reported the eldest child's death noted, "Younger brothers Robert Ray, 14, and Randy, 13, also carry the virus and are the picture of health in that they are not yet showing any signs of having developed AIDS." Moral law should have protected them from ridicule and scorn, but for better or worse, man-made justice will have to suffice.

Laws in the days of AIDS

No otherwise qualified individual with handicaps in the United States . . . shall, solely by reason of his or her handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

—from Section 504, Rehabilitation Act of 1973

Our AIDS legal issues workshop is always the best attended. It's an hour-long eye-opener because school administrators don't know that knowing whether or not a person has HIV or AIDS isn't the issue. Our behavior as a school staff is the issue. We have to treat everything as if there is the possibility of AIDS so there's no possibility of discrimination. Our job is to protect everyone in the school from the ignorance of those who are unaware, not point fingers at everyone who has HIV or AIDS.

—Allen Stephens, Region XIX Educational Service Center, El Paso, Texas

For those who may not care whether the human race survives this generation, the federal government provides a strong incentive to educators for HIV awareness. Three laws define students with HIV/AIDS as people with disabilities who cannot be discriminated against: *The Americans with Disabilities Act* (ADA), *Section 504 of the Rehabilitation Act of 1973* as interpreted by the U.S. Department of Education's Office of Civil Rights (OCR), and the *Individuals with Disabilities Education Act* (IDEA), as interpreted by the Office of Special Education and Rehabilitative Services.

Since the Office of Civil Rights (OCR) reports that the lion's share of complaints it receives involve the failure of elementary and secondary schools to comply with civil rights laws, it seems likely that HIV discrimination and rights violations will increasingly come to the fore. "How should teachers and administrators of special or regular education respond when informed that a student has tested positive for Acquired Immune Deficiency Syndrome?" asks OCR Policy Division Chief Jean Peelen in her article, *And How Else is Section 504 Different?* "Do regular education students with HIV/AIDS have anything to do with the special education system?" The answers to these questions, while still under interpretive scrutiny by OCR and other governmental rights regulators attempt to ensure equity. But the law mandating fair treatment for students with HIV/AIDS is much more nebulous than an affirmative action edict. The complexity and the loneliness of living with HIV are mirrored in a reality articulated by OCR: "Persons with AIDS are also limited in a major life activity due to the reaction of others to their perceived contagion." As a result of this unfortunate factor, since 1989, legal, medical, public health and education experts and specialists have homed in on confidentiality as one of the most important—if not the most important—rights of people with HIV disease and/or AIDS. The confidentiality rule of thumb may have been best articulated by Dr. Timothy Townsend of Johns Hopkins University: "If there's no risk, there's no need to know."

AIDS guidelines for schools like the National Association of State Boards of Education's *Someone at School Has AIDS: A Guide to Developing Policy for Students and School Staff*, advise districts to inform only the superintendent, the person's physician, and a public health official who need not know the person's name. According to the guide, AIDS patients and their families should have the right to approve whether others will be notified. Special policies for hemophiliacs and worries about children biting each other or getting scrapes on the playground were dismissed early on by the experts. But, they advise, school personnel should use the CDC's "universal precautions" when cleaning up blood spills no matter if they know of a student in the school who has HIV or not.

In addition to the right of confidentiality, precedent -setting cases such as *Ray v. School District of Desoto County*; *Martinez v. School Board of Hillsborough County, Florida*; and *Doe v. Dolton Elementary School District No. 148* held that in most, if not all, cases the student with HIV/AIDS should be educated in the classroom alongside peers. If parents

or school officials believe that any child with HIV is best served outside the regular classroom—either at home or in a isolated setting—Section 504 mandates "an evaluation and placement process to determine the appropriate educational setting for a child with AIDS." In the event of an evaluation, adherence to Section 504 again requires that placement be decided by a panel that includes the child's physician, public health personnel, the child's parent or guardian, and personnel familiar with all possible educational services. The panel should make its decision based on information from tests, teacher recommendations, and evaluations of the child's physical condition, maintains the OCR.

If the letter of the law isn't incentive enough for educators to realize the commitment government has made to ensuring the rights of people with HIV/AIDS in school and the larger society, then the spirit of its interpretation during the next few years should change their mindsets. The IDEA (formerly known as P. L. 94-142) requires that state and locally funded schools make "related services" available to students with HIV/AIDS and other disabilities as needed. IDEA defines related services as "transportation," "speech pathology and audiology," "psychological

services," "physical and occupational therapy," "recreation, therapeutic recreation, and social work services," "medical and counseling services," and parent counseling and training. IDEA also mandates that schools list related services needed by the student on that student's Individual Education Plan, *whether the district provides the services or not.* The latter requirement gives parents of children with HIV the right to find needed services elsewhere and sue the school for expenses and damages. "Under IDEA, schools can no longer ignore their legal responsibility to support students with HIV/AIDS (or any other disability) with services," explains SEDL Special Education and Rehabilitation Services Center Director John Westbrook. "If parents find the services their HIV positive children need in a private school, by law the local school must pay the bill," he maintains, adding that IDEA also ensures parents the right to independent evaluations at the school's expense, and a number of varying appeal options for any placement decisions the school hands down. In essence, notes Westbrook, the laws protecting people with HIV/AIDS are designed to place the buck—not allow schools or anyone else to continue passing it on. "Saying your school does not, can not, or will not provide the services the law requires leaves your school open to legal liabilities that have little to do with retaining confidentiality," Westbrook concludes. "Make no mistake: these laws were enacted to make schools provide services so that people can get on with the business of living with HIV or any other disability that challenges them."

Finally, because it is widely recognized as a civil rights bill for people with disabilities, the ADA protects people with HIV/AIDS from discrimination in employment, housing, transportation, and all forms of social access. Whatever form of discrimination is not expressly prohibited in Section 504 or in the regulations mandated by the IDEA, is fully covered under the ADA. This is especially true with regard to employment. In many school settings, that translates not only to students who work and attend school, but to teachers as well. In *Chalk v. U. S. District Court, Central District of California*, the court ordered that a teacher with AIDS be allowed to return to the classroom immediately because AIDS cannot be transmitted through normal classroom contact. Similarly in *School Board of Nassau County, Florida v. Arline*, the Supreme Court found that chronically-ill Ms. Arline was "otherwise qualified" to teach, ordered her reinstatement to the regular classroom, awarded her back pay, and established a precedent in the process that "persons with AIDS, including asymptomatic HIV-infected persons, are protected by Section 504," reminds the OCR.

Of course, gray areas persist. How, for example, can a school that must provide an Individual Education Plan (IEP) designed to support the student with a disability from the crib to the workplace, help but violate the confidentiality rule of thumb that so many see as vital for students with HIV/AIDS to retain their quality of life? And only time will tell what will become of the current debates on the privacy of mothers and their children who undergo mandatory testing for HIV in 44 states. (The only other U. S. citizens who must submit to HIV tests are federal prisoners and legal immigrants.) Perhaps here as in all things human educators and policymakers should rely upon compassion and common sense. Meanwhile, school administrators who wish to protect themselves and their schools from litigation must first educate themselves about the presence of HIV/AIDS and its transmission. That done, the experts advise, "act compassionately."

Logical Conclusions: The only known cure is prevention; and the only prevention is active, effective education

I've seen bright young people all over this country in an ocean surrounded by the sharks of drugs, violence, homicide, AIDS, and teen pregnancy, while we argue over which values to teach. . . .I believe the only way to heal our nation is through prevention, and prevention requires education.

—from Dr. Joycelyn Elders' Surgeon General confirmation hearings

I believe in myself as I look forward to graduating from Hamilton Heights High School in 1991. Hamilton Heights High School is proof that AIDS education in schools works.

—Ryan White, a school-aged person with AIDS whose survival of early discrimination ultimately inspired Congress to pass the Ryan White Act. Ryan lived from 1972 to 1990

A small but significant number of teenagers will develop HIV-related illness before they turn 20. A far greater number will become infected with the virus during adolescence. But more importantly far too many teenagers will adopt patterns of sexual behavior and drug use that will continue to put them at risk throughout their adult lives.

—from *Illusions of Immortality: The Confrontation of Adolescence and AIDS*, New York State Dept. of Health

Less concerned with legal issues than with public responsibility to educate students, most schools and states have designed and implemented some form of HIV/AIDS education in elementary, middle school, and high school during the 13 years since AIDS was first diagnosed. In general the education efforts have been criticized as unevenly distributed, untested, and consequently ineffective by friends and foes alike. Values discussions as well as religious, ethnic, and cultural groups balking at the mention of condoms and homosexuality all played into the demise of HIV/AIDS education before educators and publishers cranked out the first sets of age-specific curricula in the mid-1980s. But as the debate has flamed and waned and been rekindled, prevailing reason on the part of all parties has settled on one bit of deductive thinking in the teaching of teens about HIV/AIDS and its spread: *Changing behaviors is everything; changing the behavior of teens is harder than changing the behavior of adults; adult sexual behaviors relevant to HIV/AIDS transmission have not changed radically; therefore the behavior of teens is not likely to change with simple curricula prescriptions and lecture.* This reality pervades any discussion of HIV/AIDS education.

The state of HIV/AIDS education in the U.S.

I'll stake my views against anyone's regarding the caliber of the AIDS education currently going on in this country. In short, it is deplorable.

—from W. James Popham's *WANTED: AIDS Education that Works*

My parents would never talk to me about sex or AIDS. Who's going to teach people like me?

—teenaged girl in Dallas, TX, Feb., 1992

In a special pre-publication report delivered in June, 1993, entitled "Preventing HIV/AIDS in Adolescents" the National AIDS Commission called on President Clinton to improve HIV/AIDS education. Specifically, the report recapitulated consensus in the field: nothing less than "an integrated, comprehensive health curriculum" will prevent the spread of HIV. Although the Centers for Disease Control has called for the same kind of hard-hitting, no-holds-barred educational effort, educators still can't seem to agree on strategy. For example, National Association of State Boards of Education executive director Gene Wilhoit advocates local

design and implementation of HIV/AIDS education programs, stressing that the AIDS problem will be solved on the community level. Lew Armistead of the the National Association of Secondary School Principals, begged to differ: "Not every problem of youth should be dumped at the schoolhouse door," he admonished the National AIDS Commissioners. "We've got to refrain from telling locals what to teach." Arthur Ashe's warning goes unheeded, and HIV/AIDS curricula like that developed by the Texas Education Agency go unused in the state's rural schools, who incidentally have one of the fasting growing incidences of HIV infection on record. "Controversy is nothing new around sexuality," comments TEA's Tom Fleming who helped develop the state's AIDS curriculum. No matter what comes of the controversy, you can't force people to use the curriculum because it can't be mandated by the state."

The U.S. General Accounting Office (GAO) estimates that about two thirds of the nation's school districts offer some sort of AIDS education program, but most stop at tenth grade—precisely when many students seem to increase their sexual activity or initiate it. Such practices have caused some reviewers to deem HIV/AIDS education that targets middle school for a one-time education and prevention effort as too little too early. Rural districts with fewer than 450 students were less likely to provide HIV/AIDS education, according to the GAO study, even though HIV penetrated rural America virtually from the start. Perhaps that is because (as one resident of AIDS-panic-baptized Bogata, Texas, speculated) there is so little to stimulate young people in rural communities sex provides one of very few diversions.

To the contrary, the National Research Council in its 1990 treatise, *AIDS: The Second Decade*, advocates beginning education and prevention efforts before students begin making habits of risky sexual behaviors. Because the age of first intercourse is 12 years among a still-small, but significantly growing percentage of the population, they argue HIV/AIDS education and prevention should begin before adolescence. A partial solution has been to teach elementary students decision-making skills that will later segue into high school and college discussions of socializing and sexuality.

How do traditional means of educating students to the particulars of HIV/AIDS transmission and prevention stack up? *Decade of Denial* reports that "efforts to combat HIV and AIDS among adolescents are underfunded, uncoordinated, and insufficient" because limits on the explicitness of materials limit their effectiveness with teens. Logically, then, a CDC survey of high school students in 24 states revealed that while 86 to 96 percent realized HIV couldn't be transmitted by holding hands, a full 30 percent thought they could be infected by using public toilets, and only 29 to 47 percent understood that mosquitoes can't transmit the virus.

Flying in the face of conservative concerns that discussions of condoms and sexual activity provide tacit sanction, 57 percent of middle schools surveyed discuss condom use in their AIDS education courses. And some 56 percent of parents in the same study approved of the practice. "Most parents seem to agree teachers cannot avoid talking about AIDS," explained one elementary instruction coordinator in New Mexico. "Kids

are seeing these things on TV and they have questions," she added.

As he summarizes the state of education in the U.S., education evaluation expert W. James Popham, identifies at least five obstacles that thwart effective AIDS education efforts:

1) *AIDS is a new phenomenon with long-range implications that educators do not fully understand or appreciate.* Thus we witness their confusion and strategic floundering.

2) *AIDS may well be the first health epidemic for which education is the most effective response.* Thus educational leaders have not yet recognized the pivotal nature of their role as a response.

3) *Educators fail to recognize how strong an intervention is needed to make a difference.* Thus although altering the sex-related behaviors of young people is unbelievably difficult, educators stop short, offer curricula piecemeal—if at all— and tend not to want to rock the boat.

4) *Educator accountability for everything from achievement test scores to monitoring other superimposed standards has left most reluctant to take on the harder task of offering life and death HIV/AIDS instruction.* Thus schools themselves fall short of passing one of their most important tests.

5) *Finally, fear of offending religious critics stops many school administrators from championing the safer sex education and prevention strategies that students in schools desperately need.* Nowhere has this been more visible than New York City's ill-fated attempt to distribute free condoms on demand in the City's school system that remains one of the hardest hit by HIV in the nation. Thus stagnation, stand-off, and rampant HIV infection among teens. Clearly, educators need to become aware of these barriers and actively address them if the promise of education as preventative "cure" is ever to be realized.

Warning: Service providers often fail to connect with educators

People argue from two completely different vantage points when the focus is HIV education: One group represents a moral issue; the other represents a medical issue. It's like comparing an apple and an orange and trying to reach some compromise.

—Tom Fleming, AIDS curriculum co-developer, Texas Education Agency

In January of 1993, SEDL's Regional Rehabilitation Exchange (RRX) surveyed 137 HIV/AIDS service providers in the Southwestern Region. A group that prides itself on its community base of support and clients, the RRX hoped to gauge efforts by these caring professionals to provide HIV/AIDS prevention and care in Arkansas, Louisiana, New Mexico, Oklahoma, and Texas. Nearly half of the survey sample responded. The majority (62%) of those service providers thought people with HIV and AIDS needed help with securing or maintaining employment. Most were understandably familiar with the rights of people with disabilities under the ADA and said they shared that information with members of their communities. Indeed, most (59%) worked with their local school districts to promote AIDS awareness and prevention.

But more than half of the respondents also claimed children with HIV or AIDS couldn't get what they needed in the way of housing, transportation, community integration, counseling, and self-help skills from the communities they lived in. Most (67%) of the respondents didn't know the rights of children with HIV in special education under the Individuals with Disabilities Education Act. The survey's conclusion: "Most service providers do not perceive the public schools to have mechanisms in place for students with HIV that are capable of providing needed, appropriate and confidential services."

The upshot, according to RRX director John Westbrook, is that communities believe services are resonant, that someone is meeting most of the needs of people with HIV disease: "But they're not; and communities may not know it. Again, the logical locus for HIV service provision, as many have contended for years, is the schools."

Further, special needs students are at increased risk of HIV infection because they lack knowledge, information, adequate social skills, self-esteem, judgment, and because they have been trained to let others control them. Aside from the obvious concern that people with HIV/AIDS are not necessarily classified as special education students and are indistinguishable from the rest of the student population, current HIV/AIDS education efforts do little if anything to let students with HIV know of services and community resources that are available to them.

What more than ten years of a pandemic has taught the world about the best ways to educate a populace in spite of its own fear

The only thing that works 100 percent is abstinence; but we know our children are not being abstinent.

—from Dr. Joycelyn Elders Senate confirmation hearings

AIDS prevention can only be effective if it changes people's sexual behavior. . . . (I)t must be compatible with the aspirations and plans which these communities are drawing up for their development.

—from Remee Sabatier's "Different People, Different Messages"

Grateful irony. That's the best way to describe successful HIV education efforts in Rwanda, Zambia, and Uganda that have brought the AIDS epidemics in those countries from an overwhelming into a "grim, but perhaps manageable" perspective. President Kaunda of Zambia and President Yoweri Musseveni of Uganda became the lone heads of state who were personally involved in their national AIDS awareness and prevention campaigns in 1988. Both led traditional polygamous peoples who immediately stigmatized those with HIV/AIDS. Though flawed, the plans these leaders helped to develop and support saved the spirit of their traditions and yet began to protect their ravaged nations from the continued spread of HIV. Unlike residents of Polish villages who chased HIV-infected children from their beds and plastered billboards recommending that people with HIV/AIDS be isolated and their silverware boiled, some Africans in nations hit early and hard by HIV/AIDS are facing the challenge and fear head-on.

The "why" of that difference may lie in a custom blend of common sense, pragmatism, and innovation for survival. Observers argue that these three factors—enhanced by educators who stick to the facts, use blunt, everyday language, emphasize individual responsibility and self-respect, and involve all members of the group in prevention—have precipitated success in HIV/AIDS education worldwide. The best lessons are painfully logical in theory, if a bit more complex in practice. A program in Rwanda, for example, checked the spread of HIV among heterosexuals by targeting young women for education. 1,458 Rwandan women enrolled in a prevention program in 1988 in that nation's capital city of Kigali. The program provided confidential testing, education via a 35-minute video about the virus and its transmission, and a concluding group discussion. Program participants received free periodic medical examinations, free condoms and spermicides, and an open invitation to have their spouses and/or sexual partners tested and taught about the disease. After a year in the program, condom use rose from 7 percent to 22 percent, 26 percent of the women brought their partners in for testing and teaching, and the rate of

HIV infection slowed from 4.8 percent to 1.4 percent. As researcher Susan Allen reported, "No other intervention has been able to demonstrate this level of effectiveness in reducing the spread of HIV."

The lessons from the Rwanda experiment may be less elusive than they at first appear, given the simplicity and straightforwardness of the effort. Surveys of massively infected African populations showed that adults knew much about HIV theoretically and firsthand from friends and neighbors who had contracted the disease. But the knowledge was not being translated to changed behaviors—as is the case with American teens. So, educators must first meet people where they are. For HIV/AIDS educators and activists in minority communities that has meant using the "grapevine" of verbal information spread and bypassing "official" messengers who are found suspect and lacking by community members. For rural communities, outreach may mean aggressively penetrating to the root of community culture.

The international Panos Institutes' AIDS Unit identifies six practices that have signalled success in AIDS education efforts worldwide: 1) *Information alone does not change behavior.* That's why 93 percent of British teenagers surveyed knew how HIV was transmitted, but 33 to 50 percent admitted that the absence of a condom wouldn't prevent them from having sex. 2) *AIDS educators must understand and confront people's fears.* Failure in this area of interpersonal skill can increase stigmatism and panic. 3) *The source of AIDS information must be trusted; and educators must treat a drug abuser with the same respect afforded a physician.* 4) *To educate people about AIDS, it is first necessary to overcome denial and then the education effort must take actual sexual behavior into account.* 5) *Early claims that religion, culture, and ideology protect members of related groups from HIV infection have been disproven, but religion and culture are nonetheless powerful attitude-shaping tools.* 6) *Educating women about HIV/AIDS must take social and cultural situations into account.* The most important behavioral factor that increases the incidence of infection among teenaged women multiples beyond that of their heterosexual male counterparts is the low rate of condom use among women. Although female condoms are currently being tested, they are likely years from popular use among the world's teens. Until then, girls will continue to find themselves in the unenviable position of insisting on condom use by their male sexual partners who are more often than not older and thus more likely to be infected. This imbalance of power against HIV infection remains a dangerous social deterrent.

What schools can learn from the lessons

It's important that people get to know you before you're visibly sick. That way they get to know you as a person—a person with HIV disease. That's the key. It's the only way any of us survives.

—Jay Stanmore, People with AIDS Coalition, Houston, Texas

Beyond theory and philosophy, for schools that hope to prevent or slow the spread of HIV by educating their students, these world directives are clear and concrete. First, schools should focus on HIV risk *behaviors*. Then

they should help everyone, students and faculty alike, make more realistic risk estimates, emphasize skills that can ease HIV-risk situations, devote more classroom time to HIV education, and provide staff training that is as potent as the lives that depend on it. Schools should see the travesty in a GAO study finding that only 17 percent of teachers who are responsible for HIV/AIDS education have received any training. According to Dr. Robert Selverstone, Board Director of the Sex and Information and Education Council of the United States, that means acknowledging society's prevalent "eroticphobia" that teaches sex is bad and always dangerous, and listening to and "answering kids' questions seriously." At a hearing before the National Commission on AIDS, Selverstone explained that since children are bombarded with sexual messages every day in the media and on the street, they have a real need to talk about what they see and hear from a very early age. Because studies have shown that parents typically are embarrassed to discuss sexuality with their children and seek the help of educational, social, and religious organizations to help them educate and advise their children about sex, they shouldn't be surprised at their children's sexual ignorance or risky sexual behavior.

Worse, most sex education programs avoid explicit references to the very sexual acts that children see on television or among peers. While school curricula address sexuality in general terms, kids have experience that is specific and explicit. Their real knowledge is thus acquired piecemeal and their understanding may at best be fragmented. That's why, Selverstone explains, teens have plenty of questions to ask, but they aren't getting many answers. So they talk among themselves to peers who may also have more questions than answers.

Beyond targeting national eroticphobia, 13 years of dealing with the HIV/AIDS pandemic has taught people who have watched loved ones die that an upbeat, lifelong, sex-positive approach to AIDS prevention is the only way to survive. Behavior changes must be lifelong, because in all but the rarest of cases, the virus needs only one chance. Vigilant, constant reminders of the consequences of one's choices are necessary, AIDS activists in San Francisco have found, because the moment a Stop AIDS Project closes its door with the feeling that its job is done and everyone is aware of the virus, a new generation of young people comes of age knowing nothing first hand about the ravages of a pandemic. So Stop AIDS reopens amid new reports that infection is on the rise again among teen homosexual males. And the education and prevention projects continue as a matter of course, because as human beings we value life enough to work at helping others to preserve theirs.

Again, behavior modification is *the* key

We get information on HIV and AIDS all the time, but we perceive it as an effort to tell us how to behave. —**Darian Thomas, College Freshman**

You know, when I was in high school, the only thing my friends and I ever worried about was getting pregnant. We never thought about AIDS. I never got pregnant. I got infected with HIV instead. I want you guys to be careful. —**HIV positive New Mexican woman who was infected at 18**

Do your homework before you go to bed. —**AIDS prevention bumper sticker**

Though they are few and far between, evaluations of HIV/AIDS educational programs validate one truth if no other: *Only providing students with just the facts about the nature and transmission of HIV disease does not significantly change students' high-risk behaviors.* W. James Popham shares what every parent of teens ought to understand: "To avoid behavior that places them at risk of HIV infection, students need to be knowledgeable about HIV and AIDS, skilled in avoiding behaviors that place them at risk of infection, and motivated to use their HIV-relevant skills and knowledge." But, developing good interpersonal skills that promote good judgment and wise choices is a difficult task that can take a lifetime to hone. What Popham and other pragmatists advocate is helping students to start thinking in terms of self-preservation and rejecting risky behavior such as unprotected sex and drug use in peer-pressured situations. Because youth is often defined as inexperience and the unfettered belief in one's personal invulnerability and immortality, students worry more that they may offend a potential sexual partner by asking them to abstain or use a condom than about the life-threatening virus that partner could transmit.

The teaching of such interpersonal skills not only requires time, but instructional training for the teacher to first master the skills and then pass them along to students. Such instruction not only requires first rate teachers, but takes longer than the typical one-to-two hour crash course in HIV/AIDS education that students and teachers alike receive. Popham suggests a series of on-going sessions totaling 25 hours of instruction from middle school through at least the 10th grade if we honestly expect the program to influence student behaviors. He also suggests that districts train their best teachers—not just the ones with expertise in health or science but their best communicators and most interpersonally skilled staff to teach students how to protect themselves from HIV/AIDS and how to best help those who are already infected. Finally, carefully structured, same-sex, peer-led sessions can help motivate teens by providing the kind of social support students need to resist without guilt or fear.

Front-line HIV/AIDS educators and activists say the most effective strategy for reaching students in school is by introducing them to a person their age who is HIV positive. Service providers routinely report surges in HIV/AIDS testing after such PWA (Person with AIDS) presentations, but their effectiveness in changing behaviors has been disputed by studies that suggest such blunt confrontations don't eliminate denial. HIV doesn't become real for a individual until it hits someone you know, they argue, not someone who happens to share a few things in common. As one Dallas teenager phrased it, "When you hear about someone with AIDS, because you don't know them, it doesn't really affect you."

Such arguments introduce the next well-worn rule: *Adults must practice what they preach if they want to be believed by adolescents.* Since adults in the U.S. (according to a *Science* magazine survey of some 10,000 people) generally place themselves at risk of HIV infection, it's difficult to believe they can be or are convincing advocates of safer or protected sex. Adults with multiple sex partners are likely to be male, unmarried, black or white, highly educated and young. Some 70 percent don't use condoms—perhaps because they too think the disease cannot infect them personally, or because they still believe HIV/AIDS is a gay, black, Haitian or some "other-than-me" disease.

Educators and activists also argue that scare tactics don't work to change behaviors, and may in fact counteract any previous behavior modification to the point that a student begins to lose hope in successfully changing. "Exhortation," says SEDL's own internationally respected change expert, Shirley Hord, "is a poor and ineffective means of getting people to change." Hopelessness and despair, practitioners note may in fact be one reason economically disadvantaged youth engage in high-risk sexual activity in the first place. Indirectly, despair may also account in part for San Antonio, Texas, female gang initiates who boast of being required to have sex with HIV-positive male gang members. "If the (HIV) test came

up negative," explains Planned Parenthood spokesperson Jo Ann King-Sinnet, "then it was like they (the initiates) were brave enough to have unprotected sex and they were tough enough and their bodies were tough enough to fight the disease. . . . It just goes to show you . . . that they think they are invincible and it won't happen to them."

Hord proposes that HIV/AIDS educators follow a similar change process to that developed over decades of research on school change: 1) *Develop a vision of the desired change in students* (that is, safer sex and no sharing of needles); 2) *Provide training and information* (for example, a comprehensive K-12 HIV/AIDS education, prevention, and compassionate care curricula); 3) *Develop a plan to get new behaviors implemented* (such as, developing a condom distribution program, clean needle exchange, educational puppet shows, rap shows, celebrity visits, etc.); 4) *Monitor to see if the new behavior has taken hold* (in most instances, researchers use broad national surveys; perhaps smaller, more customized, one campus surveys should be attempted); 5) *Provide assistance and support for the change by building a context or environment where people will be supportive of the change* (in this case, working to calm eroticphobia).

The change process could break down, Hord cautions, in the monitoring of student behaviors. "With something as socially taboo as drug abuse and something as publicly repressed as teen sexuality," she reasons. "information must be delivered in the context of each individual caring for him or herself. Self esteem therefore plays an important role in each individual's change process. Even then, it will be difficult for change coaches or agents to monitor whether students are actively implementing the change." As in all things human, Hord warns, "change doesn't happen overnight," nor does the desired change take place in each person 100 percent of the time.

Hord's latter point seems especially true of teens who, according to Out Youth Austin counselor Lisa Rogers, usually display a wide discrepancy between self-reported knowledge of HIV/AIDS and self-reported sexual behavior. "They all know perfectly well how to put a condom on a banana, but they choose not to do it to themselves," she explains. "The latest thing we're trying is to increase student's perception of their own ability to change what they do and maintain that behavior change over the long-term." Rogers says she was encouraged in this effort by a study at the Covenant House that showed an alarming rate of high-risk behaviors for contracting HIV as opposed to an incredibly low number of the same teens who actually felt they were at risk. "Each of them saw their peers as liars who were doing everything they didn't admit to," Rogers reasons. "My fantasy is to get these young people to design a program that makes it cool to use condoms—not lie about using them. The program they design would involve creative arts and other alternatives to "just say no" which has never worked because when you are told not to think of the color blue, all you think of is the color blue. So the alternative has to be a positive. Something the students want to do on their own."

Reshuffling the race card as preface to lasting change

This disease (HIV/AIDS) is becoming the particular scourge of people who are young, black, and hispanic.

—then-U.S. Surgeon General C. Everett Koop, Sept., 1987

From the first cases of AIDS and HIV infection in the early 1980's, African Americans and Hispanics have been disproportionately affected. Information about how HIV/AIDS is contracted and spread reached minority communities much later than those in the "mainstream." The result: a repeat of the 1950s polio epidemic in which vaccines arrived late to Southern blacks and a second "black" wave of polio ensued. With HIV infection, the only vaccine is enough information to make a choice. Since the flow of information has been slow and often blocked from outside and within minority communities, minorities are currently weathering a second, race-intensive wave of HIV infection.

According to the Family Resource Center, nearly a third of the total AIDS cases in the U.S. are suffered by African Americans although as a group, African Americans comprise 12 percent of the population. Latinos, at 8 percent of the total U.S. population, are three times more likely than whites to get AIDS. AIDS is the leading cause of death among Puerto Ricans between the ages of 20 and 44 largely because of a cultural taboo against condoms, IV drug use, and the island's long-standing poverty. Among minority women the numbers are appalling: African American women in the U.S. are 13 times more likely to have AIDS than their white counterparts, and Hispanic women in this country are eight times more likely than white women to be infected by the disease.

The number of HIV/AIDS infected minority teens is no better. African Americans and Hispanics comprise 15 and 12 percent of the respective U.S. teen-aged population, but they also represent 37 and 19 percent of reported teen HIV/AIDS cases. Adding insult to injury, the average lifespan of a white person in the U.S. after diagnosis of full-blown AIDS is two years, while minority persons live for an average of 19 weeks after diagnosis.

Probable causes of the overrepresentation are maddeningly consistent with the "whys" of minority woes in the U.S.: illiteracy, poverty, inadequate transportation and communications, community economic collapse, overt and covert racism, and systemicly entrenched racial discrimination all contribute to the social breakdown that spawns low self-esteem and in turn self-destructive, high-risk behavior. Any exploration of the high incidence of HIV infection among minorities should not overlook the absence of government resources to these traditionally underserved, excluded communities. Some minority-centered organizations, like the the Urban League, cite the apportioning of funds between minorities and "gay, white males who monopolized resources in the field by default." But Hispanic AIDS Forum spokesperson Ruth Hernandez bluntly traces the fault line back to minority community leaders' own fears and denial: "Nobody wants to stick their neck out," she concludes.

Despite the overrepresentation of African Americans for example, black leaders have closed their eyes and/or failed to act quickly—if at all—to dilute the pandemic's impact on the black community. Their justification is historically understandable: With blacks disproportionately represented among prison populations, drop outs, homicides, teen pregnancies, and listed as a part—right or wrong—of every major health and social anomaly—black people (to say nothing of their leaders) were not anxious to take on yet another crisis. Further, in the early paranoid, panic-stricken years of blaming, the AIDS virus was erroneously reported to have originated on the African continent. If it's possible to dismiss and forget the early "Haitian" threat and media reports of the virus being transmitted by the eating of green monkeys who carried HIV, there are on-going reports of African students around the world who were personally blamed for the appearance of the AIDS virus. "They (Moscovites) used to refer to us as monkeys; now they point and say the word 'AIDS,'" reported one African student studying in Moscow. Likewise, Howard University Hospital's infectious disease chief, Dr. Wayne Greaves, makes it plain: "I

think blacks are afraid to speak out for fear of being identified with the problem."

But the denial of HIV's obliterating potential in the African American community may run much deeper because African Americans in particular have been lied to by federal disease prevention agencies in recent history. In the Tuskegee syphilis experiment, for example, white researchers denied treatment to a group of infected black men for 40 years so that they could trace the human course of the disease. Such historical precedent feeds a fairly common belief among some blacks that the HIV/AIDS pandemic is little more than the latest attempt by the "powers that be" to annihilate the African race. Thus, in a University of Maryland study, some two thirds of black student respondents thought it possible that "AIDS is a form of genocide against the black race." Coupled with the perceived failures of federally declared wars on poverty and drugs in minority communities, the "official" war on HIV/AIDS frankly does little save add to existing black communal disbelief and despair. And, in light of the National Commission on AIDS 1990 report that the government had "grossly underrepresented" "people of color, women, and children" in its federally funded AIDS drug and treatment trials, who's to say their suspicions have no basis in federal action—if not in policy?

Such suspicions translate into skepticism and resistance to "official" information. The sense that mainstream interests never seem to dovetail with those of minority communities further fuels the denial of HIV's spread in minority communities. At best, awareness of the seriousness of health problems like HIV/AIDS seeps in too little and too late. Because experience with the HIV/AIDS pandemic has shown that minority communities have more real and severe limitations in their financial ability to deal actively with the crisis than do other mainstream groups, their minority denial is quickly exchanged for minority despair.

In light of such frustrating realities, uneasy alliances sometimes form. For example, right-wing fundamentalists who oppose clean needle distribution to addicts whose high-risk behaviors place them and their families squarely in the path of infection, have found sympathetic ears in some African American leaders hit by two interwoven plagues—that of HIV's spread and that of drug abuse. One black New York minister, Graylan Ellis-Hagler, articulated his rage at being able to kill neither the plague rat nor the fleas it carries in the July issue of *Atlantic Monthly*: "I[illegible] they (the white establishment) push drugs in the community. They cripple the community politically and economically with drugs. They send the males to jail. Then someone hands out needles to maintain the dependency. Meanwhile, grandmothers live in fear of their own children because of what white society made them become—crack addicts, throwaways."

Meanwhile, 60 percent of New York City addicts who are known to share needles also share HIV infection, and a 1990 test tube study showed cocaine to speed up the growth of HIV by a factor of three. Thus, drugs and HIV seem destined to become ever more closely connected. But the world's HIV prevention and education efforts show us that the high rates of HIV infection among IV drug users are unnecessary. A program in Edinburgh, Scotland, claimed some success against the viral spread recently by allowing physicians to prescribe free and on demand any and all drugs addicts craved in the HIV-infected poorer city neighborhoods where over half the blood samples were HIV-positive. Although critics of the the program understandably maintain that oral dependency does little to curtail addiction, the authorities at Royal Edinburgh Hospital who began the program in 1988 report an 80 percent drop in the number of HIV-infections that can be attributed to intravenous drug use. Such experiments abroad are particularly frustrating to HIV/AIDS activists since many U.S. addicts are or were married with children who go to school and who live with HIV in their families—if not in their own personal blood streams.

To be fair, black community leaders are reacting no differently than have leaders the world over. The first place to place blame is always squarely elsewhere. With every major pestilence from the bubonic plague to this one, blame has been placed on "foreigners" and efforts made to keep the blighted foreigners out. So the U. S. holds HIV-positive Haitians in camps on the shore, while African American leaders decry the infiltration of their communities by those from outside. Students and youth who wish to enter the country are tested for HIV/AIDS along with those who request work permits, while diplomats and airline personnel take no HIV test to enter the U.S. Typically, the testing arbitrariness has hurt Third World and particularly African students most substantially, since these countries rely on universities in developed nations to educate their professional class. Since illegal immigrants must take an HIV/AIDS test to legalize their status, it's logical to say that many will stay, survive on the edge, and perhaps contract the disease in the process. So, as Renee Sabatier reasons in her book, *Blaming Others: Prejudice, Race, and Worldwide AIDS*, "the United States does not wish to import AIDS cases from the rest of the world," but in the process, the U.S. "is effectively exporting AIDS."

The last is an alarming conclusion when World Health Organization reports on world wide infection rates are considered. While infection rates have "stabilized in the millions on the African continent, Europe and North America, the part of the world with the fastest growing rate of infection is Asia. "Given its population," warns WHO Global Program on AIDS director Michael Merson, "Asia's epidemic may ultimately dwarf all others in scope and impact."

Un-counting women

The silence surrounding the (HIV) infection of young women must be broken. Girls and young women must be able to speak out, to cease to feel silenced or powerless to change what happens to them.

—United Nations Development Program 1993 HIV Report

If the treatment of racial minorities with regards to HIV/AIDS care and research has been remiss, that of women has been mis-, dis-, and until recently largely uncounted. According to the United Nations, teenaged girls now lead the HIV/AIDS pandemic in increased rates of new infection. Women between the ages of 15 and 25 make up 70 percent of the 3,000 women a day who become infected with HIV and of the 500 women who die each day from AIDS. Until 1986, women didn't die of AIDS related diseases; they died in record numbers of pneumonia and various flus but few of their physicians ever thought of testing them for HIV infection. As a partial consequence of such delayed diagnosis, according to the Women's Health Project in Austin, Texas, women die of the disease four to six times faster than men. The average length of time from diagnosis of full-blown AIDS to death for males is two to three years; while for women, it's four to six months.

As with racial minorities, the reason for the disparities may be found in early versus late diagnosis. Life-threatening gynecological diseases often contracted by women with AIDS have yet to be included in the list of AIDS-related opportunistic diseases recognized by the CDC. Undiagnosed teens with HIV may also have inexplicably recurrent vaginal infections

that their physicians tell them will disappear—with time. But for women with HIV disease such common vaginal infections may be an early sign. Because over-the-counter drugs are available for self treatment of such infections, many women treat themselves and inadvertently delay the diagnosis that could prolong their lives. In fact, reports the women's health project, many women die of AIDS-related illnesses without every being diagnosed with full-blown AIDS for these reasons.

As evidenced in the Rwandan experiment, early in the epidemic women were thought to be the best vehicle for education, given that they bear the brunt of birth control responsibility in most cultures. But as has proven the case with teens and adults, implementing the lessons of safer sex requires more than knowledge. It requires an assertiveness with her sexual partner that has been systematically socialized out of many women. "I don't want to make it sound as if women are not competent," explains Sherry Bell of the University of Texas at Austin Health Center, adding that essentially condoms are staying in well-educated and well-intentioned women's purses. "It's unfair, unfortunate, and wrong to make women the governors of sexuality."

But with the rate of HIV infected women increasing 300 percent over a year's time, one HIV/AIDS educator's 1990 prediction that the incidence of heterosexual HIV transmission to women in the U. S. would rival that of central African nation's has been tragically realized. In Africa at the worst point, men and women were infected equally. "But things have changed," explains Karen Hein, a United Nations consultant on AIDS. "What people were talking about in Africa is really happening now in this country."

Obviously, the lack of treatment that has riddled and deprived women with HIV disease and AIDS does not bode well for the teens who already top the list of groups "victimized" by other sexually transmitted diseases. Oklahoma teens have the highest rates of gonorrhea and chlamydia, while teens in Texas, New Mexico, Arkansas, and Louisiana have their own "highest" distinctions in the CDC's list of teen-hosted, sexually transmitted diseases. The reasons for disproportionate representation among female teens are both physiological and social. In addition to thinner vaginal walls, young teen women don't have the protection of thicker vaginal mucus that develops as they age. Further, researchers suspect the special cells that ring the female cervix provide particularly vulnerable conduits for HIV infection. The ring of cells is more "exposed" in teen women and women who have borne children. Further, the practice among teen girls for anal sex to prevent pregnancy and maintain "virginity" also increases their vulnerability to HIV since anal tissues are extremely susceptible to HIV infection. To remedy these increased susceptibilities, health care officials suggest developing strategies to lengthen the time before young women are pressured to have sex by peers and their own budding sex drives. Officials also advocate delaying first pregnancy, and increasing the power and ability of girls to insist on condom usage. All are fine, research-based suggestions; but none address the "how," nor its difficulty.

If not prevention, then empowered care against despair, the seventh deadly sin

At some point after that fifth (and last) HIV test, she managed to reset the balance of power. None of us could imagine how or why she found the strength to do it—and none of us ever worked up the nerve to ask her. My own theory is that she simply had to demonstrate what an outrageous error in bookkeeping somebody had made, sending her a comeuppance clearly intended for someone else. . . .She got her high school equivalency diploma. . . She got her son through elementary school on the honor roll. . . she borrowed money to move out of Brooklyn . . .

—from "The Long Goodbye" by AIDS clinic director Abigail Zuger

People with AIDS (PWAs) have crossed a certain fear threshold. They already have the disease which scares everyone half to death. They have learned to live with the fear and many of them have transcended it. We can help people to learn to overcome the fear which blinds them to the reality of AIDS.

—Richard Rector, Person with AIDS (from Renee Sabatier's "Crossing the Threshold of Fear"

In a murderous time
the heart breaks and breaks
and lives by breaking

—from "The Testing Tree" by poet Stanley Kunitz as quoted in the Tony-Award-winning play *Angels in America*

San Francisco, CA—*This week, Dr. Luc Montagnier of the Pastuer Institute, co-discoverer of HIV, said AIDS may not be an inevitably fatal disease. "There may be survivors. This is not unexpected," he said.*

—San Francisco Examiner, Oct. 15, 1992

There is still little consistency among states as to the right of a teen to authorize his or her own HIV/AIDS test or treatment for the infection if the virus is found. Employees with HIV/AIDS and the HIV-positive children of employees covered by health insurance companies still fall into the "preexisting condition" clauses fashioned more to protect the insurer than the insured. 80 percent of HIV/AIDS related costs are "covered" by Medicare programs for those who don't have or lose their insurance, but 20 percent of thousands of dollars can also be a hardship for families that often have more than one HIV-positive member. Such logistical nightmares soon prove the least of the HIV-infected student's concerns. Because schools are rarely directly connected with HIV/AIDS service providers, finding help to offset overwhelming feelings of helplessness and despair among HIV-positive teens typically is difficult.

In addition to facing the daunting health questions brought on by any physical illness, living with AIDS almost always means undergoing psychological trauma as well. That's why AIDS service provider/educator John Peter Wilhite is adamant in his advocacy for peer support groups for teens with HIV/AIDS. "I've heard the same story over and over from kids who are HIV positive: 'They gave me my test results, they asked me if I had questions, and they let me go. I didn't know who to talk to or what to do.' These kids cannot find out that they are HIV positive and be sent home with a name and a number to call. They should immediately be referred to a support group; they need to be walked through the process of reckoning with the disease and getting on with their lives."

Although the law protects the confidentiality of students and teachers with HIV, keeping that secret can be an impossible burden, as one elementary student discovered before he decided to reveal his HIV-status at show and tell time one day. Brett Lykins of Atlanta, a nine-year-old, thus made a choice that many teens choose not to make. "They're concerned about their health, but they're also concerned about how they're going to live, and who'll love them or want them now that they have this disease," explains psychologist Lisa Rogers of Out Youth Austin. Thus, advises SEDL's John Westbrook, "We need to clarify methods of empowering students with HIV while maintaining their confidentiality. Since students with HIV are living longer more productive lives, we need to teach them

how to tap into existing vocational rehabilitation programs so that they can attend school or get and keep jobs for as long as possible."

Health Care: Evolving treatment for HIV as a long-term chronic illness

We really need some type of facility for HIV-positive patients who can't afford health insurance. Patients unable to pay for medical care get on a waiting list for six to seven months at the C-100 unit (at Charity Hospital in New Orleans). There has to be a better way.

—John Thilges, East Baton Rouge Parish Health Unit

Ultimate success will depend not only on learning how best to use the drugs that are currently available and in development, but also on improving our understanding of the basic disease process so that all steps of the virus's impact on the host can be identified and countered, if not eliminated.

—from "Present Status and Future Prospects for HIV Therapies" presented by Margaret Johnston and Daniel Hoth at the 9th International Conference on AIDS in Berlin

In addition to service provision, the health care industry should not be overlooked as a deterrent to despair for those in the school who live with HIV disease. New treatments that incorporate antiviral drugs AZT and DDI with new drugs pyridionone and nevirapine in hopes of overwhelming the virus and halting its mutation are currently being researched. This new drug treatment strategy has shown promise by killing HIV in the test tube, and it's hoped that despite the mutability of the virus, combinations of drugs can be made to always stop the virus from growing.

Another recent breakthrough in HIV treatment focuses on the virus' tendency to "retreat" to the lymph nodes and attack the immune system from there for years while the infected person experiences no symptoms and the virus was once thought to be "dormant." What Dr. Anthony Fauci and his colleagues at the National Institute of Allergy and Infectious Diseases discovered is that by treating the lymph nodes early, before they have time to become established "reservoirs" of HIV infection, the onset of opportunistic infection might be dramatically delayed.

Although some persons who have been exposed to HIV and remain uninfected show signs of limited immunity to the virus, and chimpanzees have been "successfully" inoculated against HIV, massive public inoculation is at best years away. Meanwhile, AIDS researchers have postulated everything from genetic predispositions, to gene-induced cell color changes in lab rats, to weak immune systems as areas of needed research. Even if and when a vaccine is discovered, it will at best provide a complement to behavioral prevention methods. The lesson childhood inoculation efforts in this country has taught health officials is that covering the entire nation's population is almost as impossible as ensuring that no one will get the disease that's being prevented.

Thus for medical doctors, like the anonymous rural physician who told an HIV/AIDS Service provider in Oklahoma that he wanted and needed nothing in the way of HIV education because he would never have an AIDS patient, a 1990s-style reality check is overdue and ought to be mandatory for all doctors who want to keep practicing medicine. The National Commission on AIDS officialized the precedent in 1990, demanding, "It can no longer be acceptable for a physician or a dentist to offer as an excuse: 'I don't have expertise in relation to this particular disease.' They simply must acquire the expertise." Hospitals should also become better versed in HIV care, since a study by the New England Medical Center shows that AIDS patients at hospitals with little experience treating HIV/AIDS are almost three times more likely to die in that hospital than at hospitals that know how to care for those infected by the disease. The difference was most stark, the researchers found in the death rates of women with HIV at the hands of inexperienced hospital staffs. Inexperienced staff, like those in all other walks of life who had not dealt with HIV, tended not to look for the disease in women. Further, doctors tend to use drugs to combat opportunistic illnesses associated with AIDS less aggressively because they fear the drugs will harm the fetus if a woman with HIV is later found to be pregnant.

Drugs cost money; treatment costs money; and funding for HIV/AIDS must simultaneously cover the costs of effective education and prevention, direct services and care, and research and treatment. That's why a federal judge who let stand the pharmaceutical monopoly held by the Burroughs Wellcome Company who produce AZT (a drug that has slowed the spread of the HIV virus and delayed the onset of full-blown AIDS in millions of people worldwide) so disheartened those who work to ensure that "living" with HIV becomes less a euphemism and more a reality. Although recent reports question the ability of AZT to benefit everyone infected with HIV, it has been the prescription drug of choice among U. S. doctors for the past few years of the pandemic and a mainstay of hope for many with HIV disease. "The people who will lose will be the people who need AZT right now at a lower price," noted Robert Gunter, president of a generic pharmaceutical company that sought to challenge the patent held by Burrough Wellcome. Gunter claims AZT can be produced generically for about half the present price charged by Burroughs Wellcome who reported gross AZT sales of $317.2 million last year alone.

Thanks to ever-rising health care expenses, it costs approximately $80,000 to $90,000 to care for someone with AIDS from the time of diagnosis to the time of death. Since HIV infection can mean years of diminishing health and productivity before T-cell count reaches 200 or an opportunistic disease sets in, that cost is undoubtedly conservative. But perhaps tactics like the HIV Castro Village Pharmacy in San Francisco that dispenses AZT, DD1, DDC, condoms, community service, coordination with doctors, counseling referrals for caregivers to people with HIV/AIDS, and a steady flow of empathy deserve to be duplicated at school sites. "We're giving people living with HIV the basic tools of easy and quick access to medication, a community resource and assignment of insurance benefits," claims 28-year-old proprietor Paul Morabito who also admits one of the reasons for the drugstore's patronage is its commitment to service rather than self-gain and the lining of corporate pharmaceutical pockets.

HIV/AIDS and employment: Balancing compassion with the bottom line

Don't let anyone kid you—when you confront AIDS in the workplace, you will face untenable choices that seem to pit your obligation to humanity against your obligation to the organization.

—from Gary Bauza' "The Shadow that Defies Managing"

Because the Individuals with Disabilities Education Act requires that students with disabilities—including those with HIV/AIDS—work with individual education plans designed to carry each student from the cradle to the workplace, dealing with HIV on the job is not likely to remain a "shadow" issue. School vocational educators will not only need to look at special education placements, but also at the issues of confidentiality, employee productivity, and longevity in light of an all but invisible disease.

In one businessman's experience with two supervisors who contracted HIV, the ultimate issue became not so much the Americans with Disability Act that prohibits hiring and employment discrimination because of a disability, but balancing the lives of his valued supervisors who performed well until their health deteriorated against the needs and stresses placed on

co-workers as a result of HIV disease and AIDS. Of his experience with AIDS in the workplace, Gary Banas concludes: "I have no ready answers. Fatal disease permits no win-win solutions, only lose-lose ones. A manager's task is to minimize the loses—to people and organizations."

The "how" of Banas' experience is a bit more optimistic. Organizational policy always helps to ensure fairness, as does respect for the needs of all persons involved. Business-sponsored and -facilitated seminars like that of the Louisiana Health Care Alliance which teaches employees how to talk to their families about HIV/AIDS is another step in the right direction. The new attitude among businesses, according to Alliance officials is, "the company's investment in an employee doesn't end when an employee leaves work in the afternoon." In the case of teachers and administrators who contracted HIV in the Region's schools, supervisors displayed compassion. They worked with the staff with HIV/AIDS to determine what they wanted and needed to do. Those wishes were respected across the board from teachers who wanted no one to know of their illness to those who wished to be transferred out of the classroom and into administrative tasks in order to decrease their stress and increase their chances of living longer, healthier lives.

Like the service providers, Banas was shocked, but not surprised that workers who had been educated on HIV transmission would not or could not apply that information to their own lives and behaviors. Despite knowledge that HIV cannot be casually transmitted through public water fountains, toilets, shared food, or handshakes, employees still expressed concern about these daily activities as their suspicions that a coworker had HIV/AIDS grew. The HIV/AIDS service providers who were interviewed for this story also unilaterally warned employees against divulging their HIV status to employers until their health deterioration warranted it. In light of the previously mentioned legal trials in which teachers sued for reinstatement into the classroom, it would seem that their precaution may be warranted. Obviously, however, as the number of young adults infected with HIV as teens continues to grow, the presence of HIV positive teachers and administrators is bound to be felt in schools nationwide.

Hopefully, the experience of teachers and administrators who contract HIV may be better reflected by John McBeth, a popular, sixth-grade teacher in Chicago's Hyde Park, who with the help and support of his principal, advised his students of the his HIV-status. School personnel braced for the complaints and the community fear so often reported. Instead, McBeth got nothing but letters of support and encouragement from his students, and the school community raised in excess of $4,000 over a few months to help with his medical expenses.

Foreword: Policy ideals

AIDS presents a unique challenge to policy developers and implementors because it does not fit nicely into any one arena. AIDS spills over from education to health, blurring the historically familiar boundaries. . . . The linkages among values, experience and need must be defined and broadened. Perhaps a new model will emerge since the usefulness of centralism appear to be limited, at least in this national study of a controversial phenomenon— AIDS in the classroom.

—Anne Hartwig and Jane Eckhardt's Current Implementation and Practice of Educational Policy for HIV-Positive Children: A National Study

If the education community fails to address the HIV epidemic with unprecedented energy, we are surely sentencing thousands of our students to premature deaths. And in 10 years, when these young men and women are dying because they were not equipped while in school with the knowledge to protect themselves, we will have to live with the consequences of our choice.

—Bruce W. James Peyton's WANTED: AIDS Education that Works

HIV service providers don't know the education establishment. Education is afraid of community reaction should the taboos of sex and drugs that are so inextricably linked with HIV be misunderstood and misrepresented in the classroom. And policymakers have treated AIDS service providers and educators as distant cousins at best.

It's time for all that to change, says a growing cacophony of activists, educators, and providers. It's time for collaboration to become more than just a word if we are in fact to survive and overcome the despair caused by a pandemic whose indifference to education and strong morals makes it dangerous to express love. In short, as Illinois governor and incoming Chairman of the Education Commission of the States Jim Edgar put it, "We must coordinate narrowly focused programs on the one place where children spend most of the daylight hours: schools. . . .This will take bringing together education and human service agencies as a team rather than allowing them to operate independently in their own spheres."

Globally, World Health Organization AIDS Specialist Micheal Merson maintains that massive prevention efforts are the only strategy that makes sense if, as a planet, we hope to stem the tidal spread of HIV/AIDS. Although HIV/AIDS is a disease that many politicians have chosen to ignore in this country, public health policy may quicken the pace of educational change if and when President Clinton's "secure" and "universal" health insurance plan comes to pass. Touted in these early days as the promise of "Health Care that's always there" for all Americans, the long-awaited restructuring of the health system is expected to provide for better, more equitable HIV/AIDS care for all who need it.

Since the health care plan would likely not be voted on in the Congress until 1994, new AIDS "czar" Kristine Gebbie, Health and Human Services director Donna Shalayla, and Surgeon General-nominee Dr. Joycelyn Elders could, in the interim, help to lay the national policy groundwork for comprehensive, collaborative HIV/AIDS education and compassionate care. The fact that all are women brings the Rwanda experiment to mind, but more substantially all have expressed commitment to HIV/AIDS awareness, education, prevention, and care. As public health director of Arkansas, Elders spotlighted adolescents through straight talk on HIV/AIDS, the sexual abuse of children, and by advocating early, comprehensive sex education coupled with easy access to contraceptives. Her record shows fights for school-based health clinics that could dispense contraceptives on request and teach AIDS prevention. But in this, Elders is opposed by the Family Research Council (FRC) and others who argue her proposals for school condom distribution send the wrong message to the teens they say can make no safe choice but to abstain from having sex. FRC vice president Kay Coles James also argues that "a condom will protect you only two-thirds of the time during sex with someone who is HIV positive." But since condoms remain the only tangible apparatus that can prevent HIV sexual transmission, Elders is endorsed by the American School Health Association and the American Federation of Teachers. Both the latter organizations gratefully acknowledge that Elders refuses to make policy "from a lofty distance" removed from the reality, however disturbing—that teens have not, do not, and therefore likely will not abstain from having sex. They recall how Elders fought and will likely continue to fight "for giving kids information that will allow them not only to make informed choices—but to save their lives." → SEDL